

A Personal Response to the Meeting of the President's Committee for People with Intellectual Disabilities (PCPID)

Dear Policy Makers,

5-1-23

I listened with interest today to the President's Committee for People with Intellectual Disabilities (PCPID) Meeting. My understanding is that this committee provides a report to the President regarding policies that affect people with intellectual and/or developmental disabilities. I would like to express a few concerns about what I witnessed at this meeting today. I am deeply troubled that the following issues were clearly **NOT addressed**:

- The wide range of different needs/wants for people with intellectual and/or developmental disabilities, ranging from extremely limited ability to those capable of living independently.
- Person-Centered planning that includes a **full range** of options for case management, residential care, vocational support, and community living.
- Committee representation that addresses the needs/wants of ALL disabled people, instead of just one segment of the disability population, and focuses on the complex issues facing the country regarding Medicaid funding and long-term sustainability for support services instead of long personal testimonies of individual hardships. The majority of committee members should be experts in their field instead of the recipients of care.
- Unbiased, fact-based references to support systems that work well and are the preferred option for thousands of people with disabilities, as opposed to this committee's clearly biased, opinion-based references of what they believe is best for all people with disabilities.

Wide range of different needs/wants

The most glaring concern I had with this committee and meeting was the one-size-fits-all approach to disability policy. At no point in this meeting did anyone suggest that the type of disability and the level of severity should be a consideration in developing policies that affect everyone who is classified as I/DD. There is a huge difference between someone who has the adaptive ability equivalent to a typical 18-month-old and someone else who can live independently. The needs and wants of people on both ends of this spectrum, as well as the differences between those who have specific sensory or physical disabilities is extremely vast. This committee and the invited guests to this meeting were representing only those capable of independent living and speaking for themselves. While barriers to access to all aspects of community living should be addressed for everyone, **eliminating choices and options that are valued by individuals with severe disabilities should not be dismissed and discounted.** *Expansion* of support services is progressive and appropriate, while *elimination* of support services is not.

Person Centered Planning for a full array of disabilities

The first part of the meeting frequently referred to self-directed care as the "future" of disability services, with the assumption that all people with disabilities are capable of doing so.

Let me ask you this: Would you allow a four-year-old child to decide what is best for his diet? Whether he is dressed appropriately for the cold weather? How he should manage his finances? Many people with I/DD have an intellectual capacity *far below* that of a typical four-year-old. Others have extremely immature social/emotional development and cannot make safe choices. If a parent of a young child were to subject their child to the responsibilities and decisions given to some of our more severely disabled individuals through the one-size-fits-all policies that are promoted by this committee, she would be charged with abuse or neglect. Legal guardians of people with severe I/DD need to have the same leverage and respect that parents of children below the age of eighteen are given.

As a parent of a severely disabled adult daughter, I am appalled that the people with I/DD who are on this committee or spoke as guests at this meeting could speak about “person centered planning” without even acknowledging that this subset of the disability population even exists. Self-directed care is not appropriate, safe, or even within the realm of possibility for our daughter. Although our daughter has a case manager and my husband and I both have college degrees, we *still* find it difficult to manage the complexities of conservatorship, benefits, and other aspects of providing appropriate support. It is shocking that this committee feels that the “future” all people with disabilities is in self-directed care.

“Person-centered” by definition should mean that the support services are designed to best meet the needs and preferences of the individual. **For many medically fragile, mentally ill, behaviorally challenged, and severely cognitively impaired people, a specialized Assisted Living facility or campus is very often the preferred choice.** Not only are these facilities a community within themselves, they are very much a part of every community – widely acceptable for Seniors but unfortunately frowned upon for people under the age of fifty-five who need/want specialized care. The committee repeatedly referred to “community living” as the only preferred residential option. There are no facts to verify this opinion, much less the notion that congregate residential options are not “in the community”. The vast majority of people in this world live in congregate residential settings, all of which are part of “the community”. **To eliminate this choice for people with I/DD is discriminatory.**

The same is true for employment choices. Elimination of fully supported center-based options for people with severe I/DD who are neither safe nor capable of successfully working in a competitive environment is also discriminatory to the needs/wants of this subset of the disability population. Thousands of people with I/DD do not have the skills or ability to work at a competitive level or the behavioral regulation necessary to work outside of a supported, specialized environment. **Without commensurate wages and specialized support, these people would lose their choice and right to work at all.** Working for commensurate wages in a specialized work center is an informed choice that many people prefer over Adult Day Care and/or isolation at home. These issues were not even touched upon at this meeting. **People with disabilities are never prevented from working competitively and we are fully in support of expanding support services that help them access competitive employment. However, elimination of a voluntary program that works for people at the severe end of the disability spectrum will not help this cause.**

The utopian assumption that “natural supports” in the community can replace the need for Direct Service Professionals and will adequately fulfill the social/emotional needs of people who require the highest level of care is just that: an assumption. There are no facts to verify any of this and truth be told, people across all spectrums differ in their lifestyle preferences, regardless of ability. Some would very much prefer to live in an intentional community with people who have similar abilities, while others prefer to live in a more isolated setting among a mix of people. Singling out the disability population as the only demographic group who is not allowed to choose the people with whom they prefer to live, work, and socially interact is one of the most discriminatory assumptions imaginable.

Committee Representation

When decisions are made about best practices for a medical procedure, the committees who make those decisions are typically physicians who specialize in those procedures. It would be unconscionable to expect the patients to sit in on those committees to make those decisions. While they might provide input about their experiences and outcomes, they are simply not qualified to make medical decisions. The same is true for virtually any other profession. We don't call upon homeowners to tell carpenters the best way to build their house.

However, the mantra “Nothing for us, without us” uses flawed logic to justify stacking committees and boards of disability organizations and policy making with individuals who have disabilities, as if having a disability (of any kind) somehow gives them the expertise necessary to make policy recommendations to hugely complex problems, such as accessible transportation systems, housing shortages, and the DSP crisis. By definition, people with I/DD have been diagnosed with having a lower-than-average intellectual capability. While their value as human beings and their contribution to society is not questioned, these individuals are not the experts that I would choose to make policy decisions and advise the President about what is best for my daughter. It is quite possible that some of these people have never even seen a person with severe I/DD, much less have any idea what is required to provide quality care for them. They might be able to tell you how frustrating it is to have no ability to save money for a vacation if they are living off of disability benefits but have no idea how to develop money management policies.

We are facing a future of dire consequences if our country cannot gather together some of the brightest minds to help solve the complex problem of an unsustainable Medicaid/Medicare system and staggering numbers of disabled, Senior, and mentally ill people who need long-term care. Additionally, we are already in the midst of a caregiver/DSP shortage of epic proportions. The time spent in this committee grappling with these problems was so miniscule compared to the time they allowed for long testimonies about individual difficulties. While these testimonies should definitely be included as public comment to help generate lists of concerns from people with disabilities, it was a very unprofessional use of precious committee time. This time would be better spent having professionals develop strategic plans or create a list of expert consultants who can grapple with these issues.

Additionally, not a word was shared about any of the complex hardships experienced by people who have loved ones with severe disabilities, including (but not limited to): repeated police calls because there are not appropriate programs/placements for dealing with extreme behavior, prolonged ER stays because of a lack of safe, appropriate placements, aging parents who have no respite from caregiving and no alternatives for their loved ones when they die, inadequate nursing care and equipment for medically fragile adults in at-home or group home settings, extreme isolation of BOTH the individual with severe I/DD and their caregiver(s), abuse and neglect in ALL settings (including at-home residences and competitive employment settings), and the list could go on and on . . . again, no mention of these issues at any point in this meeting. It was as if this subset of the disability population did not exist.

One of the very few people who spoke on their behalf was Paul Aaronsohn who took a position that did not commit to the “HCBS-only” mantra, by supporting getting rid of the marriage penalty (which doesn’t affect most people in ICFs or living at home) and supported raising the levels of income allowed before losing benefits. Those policies make sense and do not compromise the fact that some people on the disability spectrum need other options to support a decent quality of life.

Unbiased approach to disability support options

At several points during this discussion, various people referred to either HCBS or “community living” as the only desirable living option, as opposed to “institutions”. First of all, there are no longer any “institutions” of the type connotated as Willowbrook or the asylums of the 20s and 30s. The few remaining ICFs don’t even come close to representing that model. One of the guest speakers referred to having a choice between living in an “institution” or a “mental hospital”. If the young woman did not have a diagnosis of a significant mental health disorder, she could not legally be permitted to live in either facility. Her testimony was misleading in that it appeared as if she were of sound mind at the time she was admitted. Misleading testimony can be extremely damaging to policy-making since it leads people to believe that we can take healthy people and place them in “institutions” against their will, when in fact, it is unreasonably difficult to admit mentally ill people into desperately needed treatment programs before their illness progresses to a point of permanent brain injury. This country has a dire

shortage of treatment facilities that can safely accommodate people with behavioral and/or mental health conditions, which are frequently in combination with I/DD. It is not reasonable, nor safe, to expect minimum wage DSPs in group homes or aging parents to manage severe behaviors and/or mental health conditions. Inappropriate placements, including prisons and ER rooms, have become the norm.

Secondly, it is not the size or scope of a facility or residential option that determines the quality. It is *how well it is funded*, which affects the quality of oversight, management, and staffing. Whether you call a congregate living option an ICF, Assisted Living Facility, Nursing Home, or Intentional Community, they are all options that can and *should* be the best placement choice for SOME individuals. This committee's biased approach to referring to all congregate care as "institutions" is unproductive and does not embrace their own recommendation of "person centered planning". Specialized care is a very cost effective, safe, and desirable option that absolutely needs to be part of any problem-solving conversation. The cost related to inappropriate placements (destruction of property, abuse of staff/family members, etc. . . .) has never been calculated. These are discussions that absolutely need to take place!

This committee took a similarly biased approach to their discussion about employment, with the assumption that everyone with a disability can and should work "in the community". By "community", they were referring to competitive employment as opposed to supported, center-based employment options. Truth be told, there will always be a segment of the population that is not capable of successfully working in a competitive environment or acquiring the baseline expectations for work performance and/or conduct. Many of these people can be quite successful in a fully supported setting and/or working for an accommodated wage that is commensurate with prevailing minimum wage (often referred to as "subminimum" wage). These facilities are very much a part of the community and often become the social hub for many people with disabilities. The thousands of public comments regarding the value of work centers, commensurate wage accommodations, and fully supported work options for people with severe disabilities were completely disregarded by the NDRO. This committee and meeting referred *only* to employment for those capable of independent, competitive employment.

In summary, I am deeply concerned that the PCPID did not represent the wide range of different needs/wants for people with disabilities, ranging from extremely limited ability to those capable of living independently. Their definition of "Person-Centered planning" fails to include a **full range** of options for case management, residential care, vocational support, and community living. The committee representation does not address the needs/wants of ALL disabled people, instead of just one segment of the disability population. Nor does it include experts in the field that are able to focus on the complex issues facing the country regarding Medicaid funding and long-term sustainability for support services. The committee presented clearly biased, opinion-based references of what they believe is best for all people with disabilities without referencing the needs/wants of people with severe needs.

It is time for our country to step up to the plate and come up with some real and viable solutions to these very complex issues. We cannot use human beings with severe disabilities and mental health issues as collateral damage.

Sincerely,

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